

**Cochrane Consumers and Communication Review Group
and Cochrane Australia:**

**Improving health care with evidence:
Involving the public in research and
decision making**



Facilitator's manual and resources



About this manual

Audience

‘Improving health care with evidence’ is for anyone who has an interest in how the public can be involved in health research and decision making in health care.

It has been written for a mixed audience of both lay people and professionals.

In particular it may appeal to consumer referees and members of community advisory groups.

How to use this resource

This document includes a framework of learning areas and learning outcomes designed to support people to get involved in health research and to be able to appraise evidence.

This manual has been written so that no formal scientific training is required to use it or deliver training.

Local

When facilitating this course, it is important to adapt materials to include relevant local information such as contact details and information about local groups and organisations as well as details of any local research and documentation used by those organisations.

The learning areas and outcomes will be strengthened if they are linked to specific ways the learning can be applied locally. For example, giving information about local groups or committees.

Share and share alike

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Some of the resources in this manual have been adapted from:

‘Building Research Partnerships’, created by Macmillan Cancer Support and available under the same licence. More information about that resource can be found here: macmillan.org.uk/researchlearning

Contents

About this manual.....	2
Audience	2
How to use this resource	2
Local	2
Share and share alike	2
About the course ‘Improving health care with evidence’	5
Aim of the course:.....	5
Outcomes.....	5
Timings.....	5
Programme:	6
‘Improving health care with evidence’	6
Aim of the course:.....	6
Detailed facilitation plan.....	7
Provisional timings	7
Activities.....	8
Introductions and expectations	8
Group agreement.....	8
What is research?	8
Research Methods and terminology.....	9
Public involvement in the research cycle.....	9
What is data?	10
Break	10
What is good evidence?	10
Break	11
Guest speaker	11
Appraising evidence and research	11
Agreeing next steps.....	12
Closing.....	13

Resources	14
Resource 2: Definition cards	15
Resource 3: Types of research	16
Resource 4: Blank definitions.....	17
Resource 5: Research definitions.....	18
Resource 6: Podcast: What on earth is the point of doing research if it doesn't make the patient's life better?.....	19
Resource 7: Paper: User involvement in a Cochrane systematic review.....	20
Resource 8: Highlights from "User involvement in a Cochrane systematic review"	21
Resource 9: Diagram of engagement, participation and involvement in research	22
Resource 10: Public involvement in the research cycle.....	23
Resource 11: Influenza, drugs, data and Cochrane evidence	24
Resource 12: NICE Bulletin.....	26
Resource 13: What is data?	27
Resource 14: How does data become evidence?	28
Resource 15: What did open data ever do for us?	29
Resource 16: Incredible Information! What will you share?	30
Resource 17: Questions to ask about research	31
Resource 18: Like, comment, share? "Cinnamon and Honey"	32
Resource 19: Like, comment, share? "Cinnamon and Cochrane"	34
Resource 20: Like, comment, share? "Cochrane and Honey"	35
Resource 21: Like, comment, share? "That needs some WD-40"	37
Resource 21b: Health herbs and evidence	38
Resource 22: Example news story – 'brain cancer is 'cured' after secretly being fed medical marijuana by his father'	39
Resource 23: Answering important questions using Maslow's 'hierarchy of needs'	40
Resource 24: Patient, consumer and public involvement	41
Resource 25: Skills and knowledge grid.....	44
Resource 26: Feedback Form.....	45
Resource 27: Feedback - 'What are Systematic Reviews?' - Cochrane	47
Helpful resources	48
Additional resources	49
Acknowledgments.....	63

About the course 'Improving health care with evidence'

Aim of the course:

- To learn what is meant by 'good evidence' and where you can find it.
- How the public, patients and consumers can:
 - have a role in improving healthcare decisions by understanding and sharing evidence.
 - be involved at every stage of research, including systematic reviews.

Outcomes

Participants will be able to apply their knowledge and experience in a practical way to help improve public, patient and consumers involvement in shaping the future of research and health services.

By the end of the day participants will be able to:

- Explain the terms 'research' and explain different kinds of research methodology
- Summarise the various stages of the research cycle and how the public, patients and consumers can be involved
- Explain what critical appraisal is and where to find more information
- Explain the principles of reviewing evidence
- Explain the value of systematic reviews and how this knowledge can be applied
- Summarise ways for the public to support the work of Cochrane Australia

Timings

This course is designed to be run in 4 hours, including 30 minutes of breaks.

Programme:

‘Improving health care with evidence’

Aim of the course:

- To learn what is meant by ‘good evidence’ and where you can find it.
- How the public, patients and consumers can:
 - have a role in improving healthcare decisions by understanding and sharing evidence.
 - be involved at every stage of research, including systematic reviews.

Session	Summary
Introductions and expectations	Sharing experiences and expectations of the training session
Group agreement	Establish participants’ needs and create a confidential and trusting learning environment
What is research?	An exploration of the meanings of the word ‘research’, how research is conducted and the terminology used
Research Methods and terminology	How research is conducted and the terminology used
Public involvement in the research cycle	How and where the public, patients and consumers can be involved in research
What is data?	Where does data come from, and where should it go?
What is good evidence?	An exploration of the words ‘data’ and ‘evidence’ and what is meant by ‘good evidence’
Break	
Guest speaker	A short talk with questions from a guest speaker who is involved with research, or is a member of the public involved in research (possibly systematic reviews)
Appraising evidence and research	Research in the media, research appraisal and reviewing documents
Agreeing next steps	A chance to reflect on discussions from the day and agree on future actions
Closing	Feedback forms and thanks yous

Detailed facilitation plan

Provisional timings

Session	Summary	Length	Clock
Introductions and expectations	Sharing experiences and expectations of the training session	15	9:30
Group agreement	Establish participants' needs and create a confidential and trusting learning environment	10	9:45
What is research?	An exploration of the meanings of the word 'research', how research is conducted and the terminology used	10	9:55
Research Methods and terminology	How research is conducted and the terminology used	20	10:15
Public involvement in the research cycle	How and where the public, patients and consumers can be involved in research	20	10:35
What is data?	Where does data come from, and where should it go?	15	10:55
What is good evidence?	An exploration of the words 'data' and 'evidence' and what is meant by 'good evidence'	20	11:00
Break		15	11:30
Guest speaker	A short talk with questions from a guest speaker who is involved with research, or is a member of the public involved in research (possibly systematic reviews)	15	11:55
Appraising evidence and research	Research in the media, research appraisal and reviewing documents	10	12:10
Agreeing next steps	A chance to reflect on discussions from the day and agree on future actions	5	12:20
Closing	Feedback forms and thanks yous	5	12:25

Activities

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
Introductions and expectations	Sharing experiences and expectations of the training session	-	-	<ul style="list-style-type: none"> • Introduction and Cochrane colleagues • Briefly summarise the agenda and ask everyone in the group to say their name and what they would like to get out of today. • Housekeeping (including timings of the day) 	Flip chart, pens.	15
Group agreement	Establish participants' needs and create a confidential and trusting learning environment	Everyone understands the expectations of the day and what they hope to gain from it.	<ul style="list-style-type: none"> • Participants will be able to explain what learning outcomes they have • Participants will be able to explain and recognise the importance of having a diverse group of people working towards the same objectives • Participants will be able to explain the importance of a group agreement 	<p>Ask in small groups or pairs:</p> <ul style="list-style-type: none"> • What people want to gain from the day. • What they will be able to give or offer the group (e.g. expertise/experience) • Do they have any concerns (e.g. anything they're worried about – such as acronyms or role play). <p>State the you would like to make a group agreement:</p> <ul style="list-style-type: none"> • Ask people what kind of things they'd like in the group agreement for how the group will work that day. Log these on the flip chart. (Hints: equal voice, all equal, no right/wrong answers, confidentiality, respect, different opinions are welcome, questions) <p>Agree vocabulary:</p> <ul style="list-style-type: none"> • explain the term 'public' and 'consumer' and why it will be used throughout the day • no acronyms will be used at all (other than agreed ones) • A final question that is helpful: 'is there anything specific that people want to cover that has not been mentioned'. 	Flip chart, pens.	10
What is research?	An exploration of the meanings of the word 'research', how research is conducted	<ul style="list-style-type: none"> • To help define what is meant by the word 'research' • Focus participants on the whole 	<ul style="list-style-type: none"> • Be able to explain the terms "research" and "development" and how research can affect health and social care. 	<ul style="list-style-type: none"> • Ask each delegate to give you a single word or phrase which reflects their idea/concept of what the word "Research" means. Invite participants to consider it in the widest sense. • Now ask people why we do research (typical answers are 'improves lives', 'happier', 'better quality of life'). • Ask who research is for – (everyone) 		10

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
	and the terminology used	research process, rather than just the outcomes		<ul style="list-style-type: none"> Now ask people if and why you should involve the public in research? 		
Research Methods and terminology	How research is conducted and the terminology used	<ul style="list-style-type: none"> To introduce some of the language and methods of research. 	<ul style="list-style-type: none"> Be able to explain the different methods of research used (including systematic reviews) and the language used to describe it Explain what critical appraisal is 	<ul style="list-style-type: none"> Explain that there are a variety of research methods. Explain that the terminology is there to ensure everyone, both those doing the study as well as anyone enquiring about it, understands the process under which that particular research study is being undertaken Distribute the 'Types of research' resource and the 'Blank definitions of research' 	<ul style="list-style-type: none"> Definition cards [Resource 2] 'Types of research' [Resource 3] 'Blank definitions of research' [Resource 4] 'Research Definitions' [Resource 5], 	20
Public involvement in the research cycle	How and where the public, patients and consumers can be involved in research	To use the research cycle as a basic model for understanding the different stages of the research process and to explore the added value of public and	Participants will be able to explain: <ul style="list-style-type: none"> The various stages of the research cycle. The importance of involving the public at every stage and the ways people can get involved. The difference between 'patient and carer' involvement, 'lay' 	<ul style="list-style-type: none"> Give some people cards with a stage of the research cycle and to sit or stand in a circle and hold up a stage of the research cycle. Then ask people to move around until they are standing in order. Hand out relevant information about their organisation or Cochrane. Ask them where they think they public/consumers are currently involved. Ask them where they think they could be involved. Hand out 'Public involvement in the research cycle' [Resource 10] and 'Diagram of engagement, participation and involvement in research' [Resource 9] 	<ul style="list-style-type: none"> Pieces of paper with research cycle written on them 'Public involvement in the research cycle' [Resource 10] 	20

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
		consumer involvement	involvement and that the word 'public' encompasses them all, but sometimes needs articulating.		<ul style="list-style-type: none"> 'Diagram of engagement, participation and involvement in research' [Resource 9] 	
What is data?	Where does data come from, and where should it go?	To explore the concept of data	<ul style="list-style-type: none"> Be able to explain what data is Explain different kinds of data Explain how data is and could be shared 	<ul style="list-style-type: none"> Ask what is 'data' and 'what is evidence' Explain there are two kinds of data – qualitative and quantitative "How would you describe the temperature?" would gather qualitative data. 'What temperature does the thermometer say the room is?' would gather quantitative data. Ask for anyone to give other examples of qualitative and quantitative data. Ask which is more important. Lead a short facilitated discussion. State they are both equally important if we want to have complete and holistic understanding and knowledge. Handout 'what is data?' [Resource 13] and 'How does data become evidence?' [Resource 14] Data still needs to be analysed. Sharing data and sharing results are different things. This is how data becomes evidence Talk about data sharing – ask people who owns data from science paid for by taxes? Mention 'What did open data ever do for us?' [Resource 15]: On library table 	<ul style="list-style-type: none"> Resource 13: what is data? Resource 14; How does data become evidence? Resource 15: What did open data ever do for us? 	15
Break						15
What is good evidence?	An exploration of the words 'data' and 'evidence' and	To introduce the concept of good evidence and explore	<ul style="list-style-type: none"> Be able to explain the words 'evidence' and 'data' 	<ul style="list-style-type: none"> Show the animation on systematic reviews, handout [Resource 27] Work through the influenza example 'Influenza, drugs, data and Cochrane evidence' [Resource 11]. Cut out all the stages and ask 	Resource 11: Influenza, drugs, data and	30

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
	what is meant by 'good evidence'	different types of good evidence.	<ul style="list-style-type: none"> Explain how data is and could be used to improve decision making in healthcare. Summarise what is meant by the term 'systematic review' Explain who the Cochrane Collaboration are and why their systematic reviews are considered 'good evidence'. 	<p>people to volunteer to read a stage in order. Ask what people think about the story.</p> <ul style="list-style-type: none"> Mention we will be asking guests to speak in the next section 	Cochrane evidence [Resource 27]	
Break						15
Guest speaker	A short talk with questions from a guest speaker who is involved with research, or is a member of the public involved in research (possibly systematic reviews)		<ul style="list-style-type: none"> 	<ul style="list-style-type: none"> Ask for guests to speak about how they have used evidence in their work and or how the have involved the public . 	<ul style="list-style-type: none"> 	15
Appraising evidence and research	Research in the media, research appraisal and	Explore how our perceptions of research are	<ul style="list-style-type: none"> Explain how research is often portrayed in the media and the 	<ul style="list-style-type: none"> Hand out examples of information [Resources 18-22]. Share guide for checking and challenging information on social media. 'Incredible information – what will you share?' [Resource 16] Handout 'Questions to ask about research' [Resource 17] 	<ul style="list-style-type: none"> [Resources 18-22]. 'Incredible information – 	40

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
	reviewing documents	affected by media coverage and to understand how research and evidence is appraised.	subsequent public opinion. <ul style="list-style-type: none"> • Explain what critical appraisal is. • Explain how the public can be involved in improving public health by appraising evidence to inform health practice and policy. 	<ul style="list-style-type: none"> • Mention resources on library table about involving the public and things to think about: [Resource 23]: Answering important questions using Maslow's 'hierarchy of needs' [Resource 24]: Patient, consumer and public involvement [Resource 25]: Skills and knowledge grid 	what will you share?' [Resource 16] <ul style="list-style-type: none"> • 'Questions to ask about research' [Resource 17] • Resource 23: Answering important questions using Maslow's 'hierarchy of needs' • Resource 24: Patient, consumer and public involvement • Resource 25: Skills and knowledge grid 	
Agreeing next steps	A chance to reflect on discussions from the day and agree on future actions			<ul style="list-style-type: none"> • Return to flip chart • Any actions? • Mention 'who I met' sheet. 	<ul style="list-style-type: none"> • 	10

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
Closing	Feedback forms and thanks yous					10

Resources



Resource 2: Definition cards

A. Research done in an environment (a laboratory) in which the team are able control and simulate clinical conditions or situations.

This research may include animal experiments or computer modelling.

B. Research that seeks to understand the experiences that people have in their lives. It captures knowledge that cannot always be counted in numbers.

It may be conducted by interviewing or observing people, using questionnaires or by reviewing case notes or diaries.

C. The researcher gains information about a particular problem or situation with the assistance of those who participate in the research.

It looks for solutions by carrying out ‘an action’ which is then reviewed to see whether it has addressed the problem. The process will be repeated until a satisfactory solution is found.

D. Research that studies a group of people who are free from disease but have been exposed to a potential cause of that disease.

These people may be compared with a control group that is similar but has not been exposed to the potential causal factor/s. Groups are followed up into the future to see what happens.

E. Research in which participants are randomly allotted or assigned to one of two groups.

One is the research group receiving an intervention, and the other is the control group receiving conventional treatment, no treatment or a placebo. Participants in both groups are monitored to see if any differences emerge.

F. Research that studies a group of people with a particular disease (an outcome of interest).

Researchers look back in time to see what those people may have been exposed to in order to identify possible causes of the disease. This is compared with a suitably matched but unaffected group.

G. A review of all the research studies that have been conducted into a particular topic where they have been systematically identified, appraised and then the results summarised according to pre-determined criteria.

This is usually carried out with randomised controlled trials but could also be used with other types of research studies.

H. A term used to define research to test new treatments and diagnostic procedures for all diseases.

Research begins in the laboratory and covers all stages of experimentation up to and including transfer to ‘first in human’ clinical testing. Sometimes known as ‘‘from the bench to the bedside’’

Resource 3: Types of research

Match the definitions to the letters

Action research



Systematic reviews



Randomised
controlled trial



A case control
study



Translational
research



Qualitative
research



Laboratory
research



A cohort study



Resource 4: Blank definitions

Fill in the types of research to match the definitions

A:

Research done in a controlled environment in which the team are able to control and simulate conditions or situations. This laboratory research may include animal experiments or computer modelling.

B:

Research that studies seeks to understand the experience that people have in their lives. It captures knowledge that cannot always be counted in numbers. It may be conducted by interviewing or observing people, through questionnaires or by reviewing case notes or diaries.

C:

The researcher gains information about a particular problem or situation with the assistance of those who participate in the research. It looks for solutions by carrying out an action which is then reviewed to see whether it has addressed the problem. The process will be repeated until a satisfactory solution is found.

D:

Research that studies a group of people who are free from disease but have been exposed to a potential cause of that disease. These people will be compared with a control group that is similar but has not been exposed to the potential causal factor/s. Groups are followed up into the future to see what happens.

E:

Research in which participants are randomly allotted or assigned to one of two groups. One is the research group receiving an intervention, and the other is the control group receiving conventional treatment, no treatment or a placebo. Participants in both groups are monitored to see if any differences emerge.

F:

Research that studies a group of people with a particular disease (an outcome of interest). Researchers look back in time to see what those people may have been exposed to in order to identify possible causes of the disease. This is compared with a suitably matched but unaffected group.

G:

A review of all the research studies that have been conducted into a particular topic where they have been systematically identified, appraised and then summarised according to pre-determined criteria. This is usually carried out with randomised controlled trials but could also be used with other types of research studies.

H:

A term used to define research to test new treatments and diagnostic procedures for all diseases. Research begins in the laboratory and covers all stages of experimentation up to and including transfer to 'first in human' clinical testing. Sometimes known as 'From the bench to the bedside'

Resource 5: Research definitions

Some different types of research methods

A. Lab research: the researcher has total control over the environment and what happens to the sample.

B. Qualitative Research: Is the room warm enough?, each of you will have a different answer depending on how you feel and if asked to judge it from 1 to 10 will probably have a range of answers.

C. Action Research: when the water was contaminated in a reservoir the scientists needed to work out how to destroy the bug and make the water safe again so they tried various ways of treating the water e.g. did that work, yes/no, why, try this, what did that do, try this, etc.

D. Cohort Study (forward arrow) the Chernobyl radiation leak. Those exposed to radiation have been monitored to see the effects alongside another similar group not exposed. The study is to see what are the effects of the exposure compared to the control group.

E. Randomised Control Trial: two groups of people, of a similar mix of age, sex, disease etc are compared when testing a new treatment on one group against the current treatment on the other. Randomization allows the results to be as impartial as possible. Most clinical trials are Randomised Controlled Trials (RCT's).

F. Case Control Study: a group of young asthma sufferers were investigated to see if living in a damp house affected/caused the asthma. Scientists looked back at the life of each child to see if they could identify similar conditions that would help them find a cause that matched most/all of them.

G. Systematic Review: Systematic reviews compare all relevant randomised controlled trials in health care or all comparable kinds of research. For example, in 1993 the Cochrane Collaboration led a review that compared similar research that had been done around the world to determine how effective giving steroids to premature babies was as all previous trials had been inconclusive. The review compared all similar trials and concluded steroids saved lives.

H. Translational research: Also known as ‘‘from the bench to the bedside’’ this describes the process of designing/discovering a treatment in a laboratory and then the process it goes through till it is tested on humans in clinical trials. You ‘‘translate an idea into an action’’.

Resource 6: Podcast: What on earth is the point of doing research if it doesn't make the patient's life better?

Below are quotations from a podcast published by BioMed Central following the recent publication of a paper about the methods for user involvement in a Cochrane systematic review update. The podcast can be found here: <http://blogs.biomedcentral.com/on-medicine/2015/05/27/research-to-better-patient-life/>

“I felt it was very important to get the question right and get the question from the point of view of the users of the evidence rather than just us as researchers.”

Alex Pollock, lead author of the review update, from Glasgow Caledonian University

“What on earth is the point of doing research if it doesn't make the patient's life better?”

Heather Goodare who contributed as a user. Since her husband's stroke in 2007, Heather has been involved in stroke medicine research as a carer

“I think it was always envisaged that consumers, patients, carers would have a strong voice in Cochrane, and there certainly are groups that have taken that on really whole-heartedly”

“Involving the public in developing and improving the protocol allows for a more reliable and useful study to be carried out”

David Tovey, Editor-in-Chief of the Cochrane Library,

“It's not actually about adding to our knowledge base for the sake of adding to the knowledge base. It's about adding to the knowledge base in order to deliver better treatments, better care, more effective interventions, and longer, happier lives.”

“It is important that patients and carers are involved from the beginning”

Richard Stephens, co-Editor-in-Chief of *Research Involvement and Engagement*,

Resource 7: Paper: User involvement in a Cochrane systematic

This paper describes methods used to involve patients, carers and health professionals in an update of a Cochrane systematic review and explores the perceived impact of involvement.

The full paper can be found here: <http://www.systematicreviewsjournal.com/content/4/1/55>

User involvement in a Cochrane systematic review: using structured methods to enhance the clinical relevance, usefulness and usability of a systematic review update

Methods

We sought funding and ethical approval for our user involvement. We recruited a stakeholder group comprising stroke survivors, carers, physiotherapists and educators and held three pre-planned meetings during the course of updating a Cochrane systematic review. Within these meetings, we used formal group consensus methods, based on nominal group techniques, to reach consensus decisions on key issues relating to the structure and methods of the review.

Results

The stakeholder group comprised 13 people, including stroke survivors, carers and physiotherapists with a range of different experience, and either 12 or 13 participated in each meeting. At meeting 1, there was consensus that methods of categorising interventions that were used in the original Cochrane review were no longer appropriate or clinically relevant (11/13 participants disagreed or strongly disagreed with previous categories) and that international trials (which had not fitted into the original method of categorisation) ought to be included within the review (12/12 participants agreed or strongly agreed these should be included). At meeting 2, the group members reached consensus over 27 clearly defined treatment components, which were to be used to categorise interventions within the review (12/12 agreed or strongly agreed), and at meeting 3, they agreed on the key messages emerging from the completed review. All participants strongly agreed that the views of the group impacted on the review update, that the review benefited from the involvement of the stakeholder group, and that they believed other Cochrane reviews would benefit from the involvement of similar stakeholder groups.

Conclusions

We involved a stakeholder group in the update of a Cochrane systematic review, using clearly described structured methods to reach consensus decisions. The involvement of stakeholders impacted substantially on the review, with the inclusion of international studies, and changes to classification of treatments, comparisons and subgroup comparisons explored within the meta-analysis. We argue that the structured approach which we adopted has implications for other systematic reviews.

Resource 8: Highlights from “User involvement in a Cochrane systematic review”

Below are some key quotations from this paper about user involvement in a Cochrane Systematic review. The full paper can be found here: <http://www.systematicreviewsjournal.com/content/4/1/55>

- The act of professionals and consumers working together to produce and share knowledge has been an explicit principal of the Cochrane Collaboration since it first began.
- This involvement is beneficial to the quality, relevance and impact of health research.
- The active involvement of people with a health condition has been proposed as a way to enhance the perceived usefulness of systematic review evidence, addressing barriers to the uptake of synthesised research evidence
- A wide range of different approaches to involvement has been implemented. This review found that the most commonly used approaches are:
 - consultation with a group of people at a one-off workshop or at key stages in the review process
 - involvement of individual people as members of a review team
 - email consultation
 - using a Delphi process
- Developing effective methods of involvement for systematic reviews is made difficult because of ‘poor descriptions of involvement within many reviews’ and by ‘limited evaluation of the impact of involvement’.
- A number of strategies are recommended to facilitate effective involvement within systematic reviews. These include:
 - Budgeting for the costs of involvement
 - Having a review team member with lead responsibility for involvement
 - Providing training, briefing notes and background information to people involved
 - The use of structured methods of involvement (such as the nominal group technique or Delphi process) at key stages of the review process

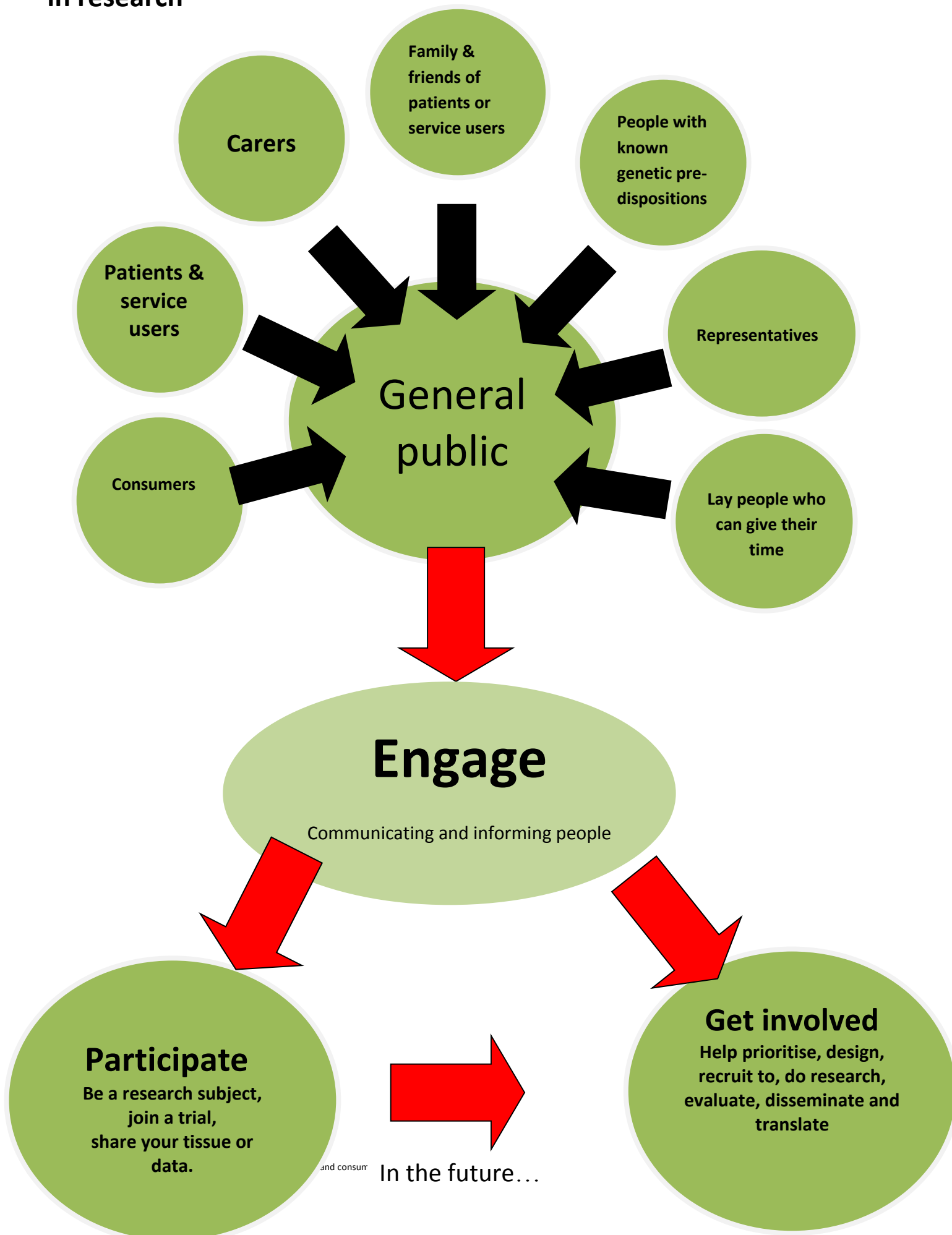
Results

- ‘...I have taken part in quite a number of things of this nature over the past 20 years and this is the first time that I have really felt that it has been successful and that I have been listened to..’
- With appropriate planning and resources, user involvement can be integrated into the process of updating a complex review and timely completion of the review achieved
- user involvement within a systematic review has the potential to enhance the clinical relevance, usefulness and usability even when focused on the most ‘simple’ of interventions.

About the language used

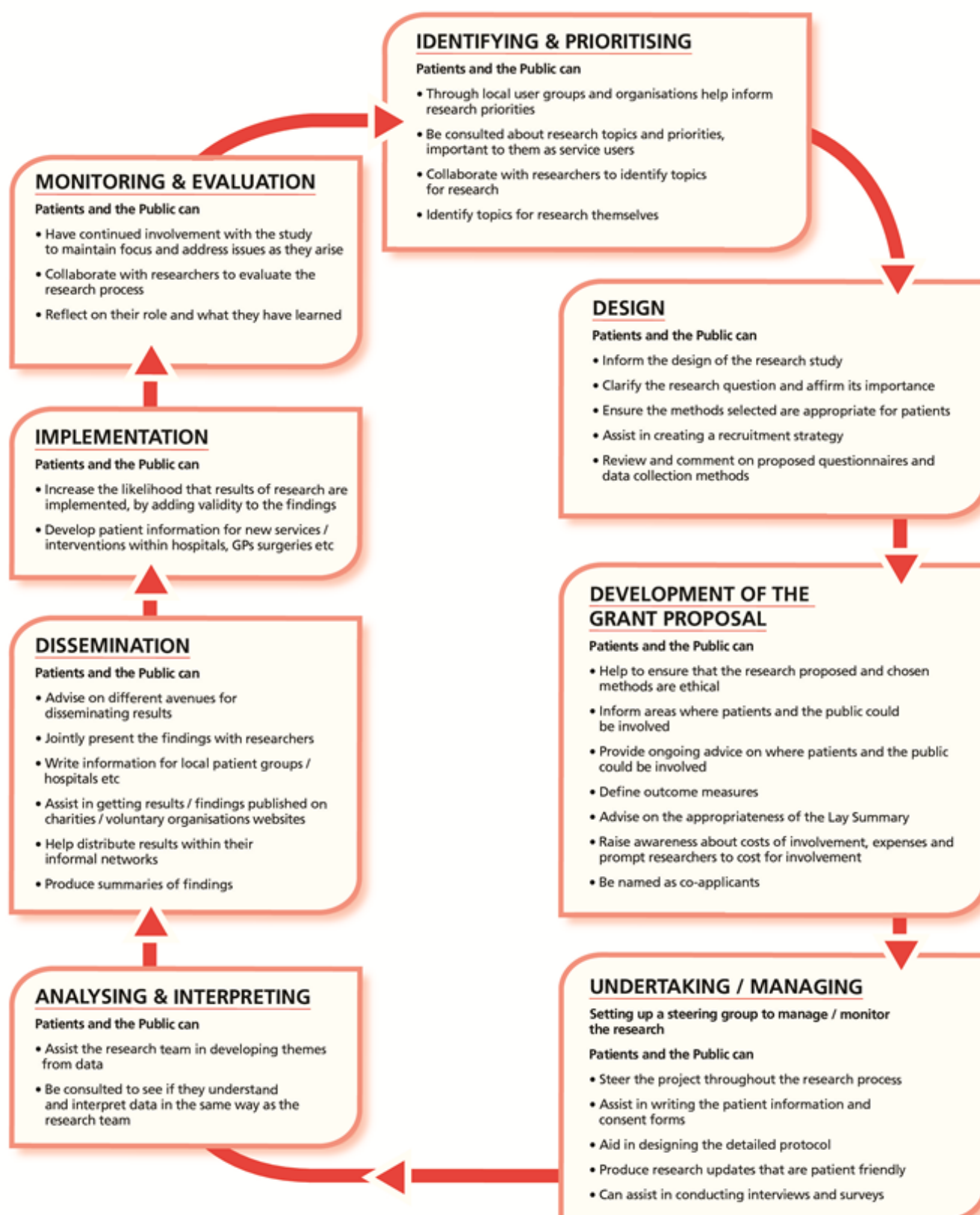
There is no agreed definition of the term ‘consumer’ and lack of agreement that this is the best term to use. For the purposes of this paper, we define ‘consumer’ as a person with a healthcare condition, or friend, carer (unpaid) or family member of that person... within this paper, we have chosen to primarily use the term ‘user involvement’, as we felt that this clearly includes all ‘users’ of health information, including consumers, members of the public and health professionals.

Resource 9: Diagram of engagement, participation and involvement in research



Resource 10: Public involvement in the research cycle

How to incorporate patient and public involvement in the research process



Resource 11: Influenza, drugs, data and Cochrane evidence

Timeline	What happened
1918	500 million people across the world were infected by the 1918 flu pandemic and between 50 to 100 million are killed. One third of the world's population was infected and 3-5% killed. In Australia, 12,000 were killed. This makes it one of the deadliest natural disasters in human history.
1920s-90s	The influenza is described by some historians as the 'forgotten pandemic' ¹
1990s	News about bird flu and other pandemics in the 1990s onwards renews public awareness and concern about influenza outbreaks.
1996	"Oseltamivir" discovered by scientists using shikimic acid, an extract of Chinese star anise. <i>Oseltamivir is absorbed by the liver, it is processed and acts as an inhibitor for an enzyme involved in the reproduction of the virus.</i> 20 year patents relevant to Oseltamivir were sold to Roche and they name it 'Tamiflu'.
1999	In the USA, the Food and Drug Administration approved Oseltamivir for treatment of influenza in adults based on two double-blinded, randomized, placebo-controlled clinical trials. The trials were sponsored by Roche ² .
2005	Oseltamivir was widely used during the H5N1 avian influenza epidemic. Governments around the world, including Australia and the UK stockpiled the drug. The Australian government currently has a stockpile worth \$192 million and the USA has spent more than \$1.3 billion ³ .
2006	A Cochrane review raised controversy by concluding that oseltamivir should not be used during routine seasonal influenza because of its low effectiveness, stating it does 'not prevent infection or interrupt voidance of viruses from the nose' ⁴
2009	The public and Governments around the world accept "some drug companies have airbrushed out bad results by not publishing them, which could result in a drug appearing to work better and more safely than it does in reality" ⁵ . Drug companies may sell the public drugs which have been approved based on evidence which they have selected themselves for publication. Often, even regulators have not seen all the information about human clinical trials. The "entire ecosystem of drug evaluation and regulation is deeply flawed" ⁶ .
2010 - 2012	Cochrane are denied Roche's full clinical study reports.
2013	'All Trials' is launched and calls for 'all past and present clinical trials to be registered and their results reported' and data to be shared openly.
2014	Cochrane reviews all the previously un-released clinical study reports (detailed documents from the commercial sponsors of the trial). The reports involved more than 24,000 people. The review highlights that oseltamivir (and similar compounds) are not proven to 'reduce hospitalisations and serious complications' and 'lead to harmful effects that were not fully reported in the original publications'. ⁷ Deliberate publication bias made Tamiflu look 'better than it really was'. ⁸
2016	Roche patents expire, anyone can make the drug without a paying licensing.

At present, it is still legal for pharmaceutical companies to withhold data from human clinical trials.

Sign the campaign at alltrials.net



¹ America's Forgotten Pandemic: The Influenza of 1918, Crosby, 2004

² http://www.accessdata.fda.gov/drugsatfda_docs/nda/99/21087 Tamiflu.cfm

³ <http://www.news.com.au/lifestyle/health/government-spends-192-million-stockpiling-roche-drug-tamiflu/story-fneuzlbd-1226880199762>

⁴ <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001265.pub2/abstract?sessionid=CD001265.pub2>

⁵ <http://www.theguardian.com/business/2015/may/18/drug-trials-firm-to-challenge-plans-for-greater-transparency-over-results>

⁶ <http://www.bmj.com/content/348/bmj.g2630>

⁷ <http://community.cochrane.org/features/tamiflu-and-relenza-getting-full-evidence-picture>

⁸ <http://news.sciencemag.org/biology/2015/01/tamiflu-helps-newest-study-long-running-debate-says>



Resource 12: NICE Bulletin

Here is a 'Public Health Evidence Awareness' Bulletin sent via email (PDF format):

<http://www.nice.org.uk/media/default/About/what-we-do/Evidence%20Services/Public-Health-Awareness-Bulletins/Nice-public-health-evidence-awareness-bulletin-june-2015.pdf> (some formatting changed)

What is good, what could be improved?



Population groups

[Children and young people](#)

[Older people](#)

Settings

[Schools](#)

Service delivery, organisation and staffing

[Service improvement](#)

Lifestyle and wellbeing

[Alcohol](#)

[Diet, nutrition and obesity](#)

[Smoking and tobacco](#)

Health protection

[Environment](#)

[Infections](#)

Children and young people

[Food supplementation for improving the physical and psychosocial health of socio-economically disadvantaged children aged three months to five years: a systematic review](#)

Campbell Collaboration

This systematic review examines the effectiveness of supplementary feeding interventions, alone or with cointervention, for improving the physical and psychosocial health of children in low socioeconomic groups aged 3 months to 5 years.

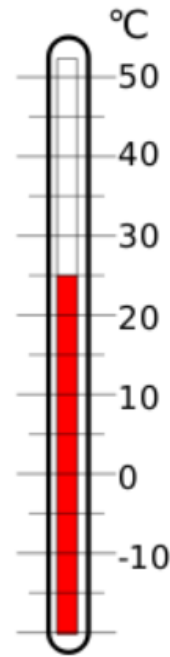
[Back to top](#)

Resource 13: What is data?



Qualitative data is **subjective**, recording how **subjects** (e.g people) communicate the **qualities** of their experience.

"How would you describe the temperature" is a question which would gather qualitative data



Quantitative data is **objective**, recording how measurable and **quantifiable** things, **objects** and people behave and interact.

"What is the temperature in Celsius?" is a question which would gather quantitative data

They are both equally important if we want to have a complete and holistic understanding and knowledge.

Both these kinds of data are given meaning by the process of interpreting it.

Resource 14: How does data become evidence?

What is science?

Science means knowledge.

We know things because we can observe things.

These observations can be expressed as data.

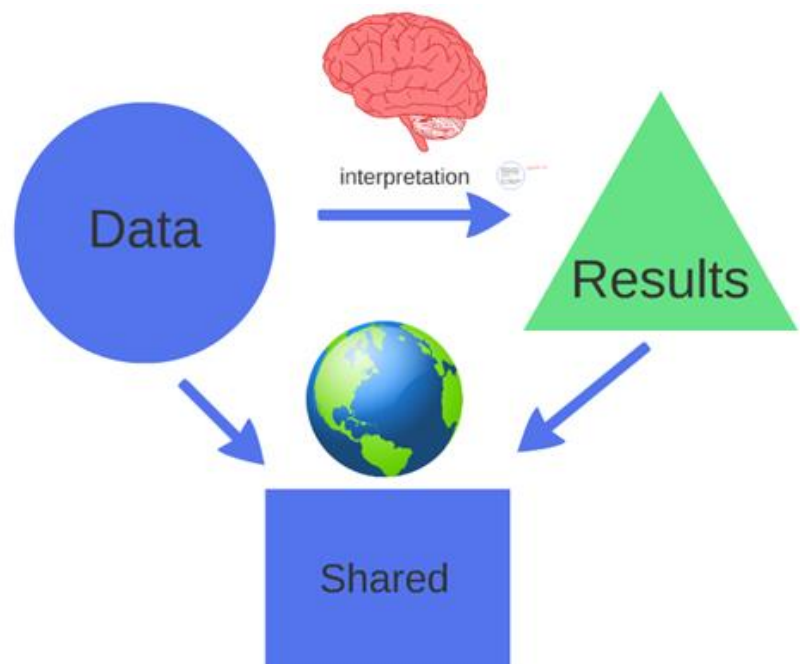
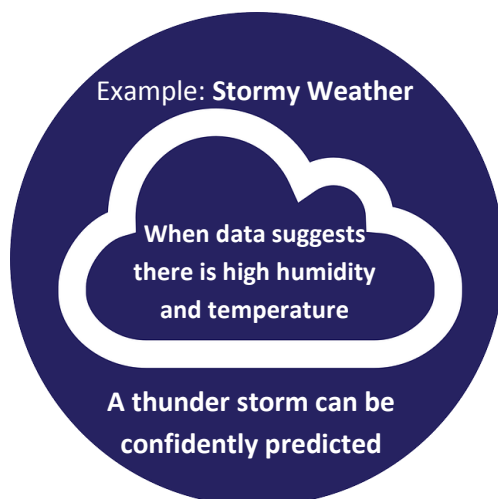
What is research?

Research is a way of trying to answer a question.

Good research uses a method which is regulated and reviewed by the public and scientists.

It often involves collecting and interpreting information in the form of data.

Interpretation sometimes involves spotting patterns, which makes it possible to make predictions or give explanations.
If the predictions are reliable, this is how interpreting data can provide evidence.



If researchers share:

- the data itself
- their results
- the method of how they gathered the data

Then other people can:

- check they agree the method was appropriate
- interpret the data themselves
- agree or disagree with the results
- Spot new patterns, make additional predictions or give alternative explanations.

The more data there is, often the clearer and more predictable the patterns are, and the data can be said to provide evidence that we can make predictions.

If data and results are shared, researchers can use and build on this knowledge in the future. This process makes researchers more confident when recommending actions.

Remember: Sometimes the correct response to a question is 'We don't have enough data to give an answer'

Resource 15: What did open data ever do for us?

Australia and the UK are [leading the world](#) on open data. Open data is publicly released raw data (for example all collected data, not statistics), often from the government or public services, which is made available to everyone so they are free to use or reuse it any way they like. While it can be read by individuals, for example in a spreadsheet, it is primarily designed to be 'machine-readable', so it can be inserted directly into computer programmes (written by those inside or outside government).

Data.gov.au provides an easy way to find, access and reuse public datasets from the Australian Government.

The Governments of Australia and the UK have made releasing open data a priority because:

1. It makes the government more accountable to citizens and strengthens our democracy
2. It brings us better public services, as everyone can help monitor and improve
3. It feeds economic and social growth

What brings open data to life is how people use it. And in the few short years since we started releasing it, there have been hundreds of examples. A few illustrative uses made of open data are listed below.

Taken from: <http://data.gov.uk/blog/what-did-open-data-ever-do-us> [30.1.14]

What is Linked Data?

Part of Sir Tim Berners-Lee's original vision of the Web was that it should also be used to publish, share and link data.

The Linked Data Web is not just about connecting datasets, but about linking information at the level of a single statement or fact. The idea behind the Linked Data Web is to use uniform resource identifier or URIs (these are like the uniform resource locators or URLs you type into your browser when going to a particular website) to identify resources such as people, places and organisations, and to then use web technology to provide some meaningful and useful information when these URIs are looked up. This 'useful information' can potentially be returned in a number of different encodings or formats, but the standard way for the linked data web is to use something called RDF (Resource Description Framework).

Taken from: <http://data.gov.uk/blog/what-is-linked-data> [30.1.14]

Consider how open and linked data might change the future of research

Resource 16: Incredible Information! What will you share?

The internet and social media allows anyone to share any information on an equal platform. Governments, charities, researchers and many health promotion organisations use social media to spread their messages and trustworthy information.

However, there are also many sources of information that are not trustworthy or credible. While many may be created with the best of intentions, some are often deliberately disguised to look credible. Examples include:

- People working on behalf of for-profit organisations, who seek to misinform vulnerable people and sell products to them based on misinformation.
- Individuals and members of organisations which consider their ideology to be more important than current scientific evidence.

While the above definitions could arguably include both Governments and pharmaceutical companies, more often these definitions more accurately describe smaller organisations.

Is that right?

If you find yourself reading something and asking this question, here are some tips:

- Is it clear who the author is? Are they qualified? Is it shared by a reputable organisation?
- Does the information use sources that link to “peer reviewed” evidence?
- Does it feel like someone is trying to sell something, or that it advantageous for **them** to change **your** mind?

I want to believe

Ask yourself, do you want to believe something in particular? If so, why? Try and imagine you want to believe the opposite and look for evidence to back up that perspective. This can be a helpful way of trying to be objective.



I've seen something incredible - what do I do?

Wikipedia is always a good starting point to check information. Wikipedia can be written and edited by anyone. This powerful tool allows anyone to check information and verify sources. While there are inaccuracies on Wikipedia, it is generally agreed that it is a reliable starting point to find out more information about most things. The journal *Nature* reported that Wikipedia “comes close to Britannica in terms of the accuracy of its science entries”.

Top tips for using WIKIPEDIA

- Check citations and links– are they trustworthy? (does it link to peer-reviewed research, or Government information).
- Is the link broken? Try archive.org/web for a ‘time machine’ of saved pages on the internet.
- Spot an error or mistake? Correct it! Editing Wikipedia is quite easy, and even if you get it wrong, other ‘Wikipedians’ will often check and correct your mistakes.

Health related?

Search for “Cochrane” and the “health related subject you want to learn more about”. Often, a Cochrane review will be at the top of most search engines .



Remember:

Check before you share, challenge if it's dangerous!

Resource 17: Questions to ask about research

Questioning everything is at the root of scientific understanding, that's what gives us knowledge. Good research attempts to answer questions using a rigorous method to give results.

Critical appraisal is a way of looking at published or reported research and asking questions about the validity of the methods, the results and how published findings can be acted on.

Below are some basic questions to ask of any research before it moves on from the design stage.

When answering these questions, try to start with what is good, and then move onto what could be improved.

Ethics – Are the participants being recruited in an acceptable way? Is it possible to have informed consent? Are participants paid and is this relevant? Are participants exposed to unnecessary risk? Are the exclusion criteria appropriate or too excessive? (e.g. gender, age or being pregnant are common exclusion criteria)

Need – Does the research question address something of importance to the public and patients? Does it look at clinical need or an uncertainty about current treatment or services?

Public involvement – Do you think the public and consumers have been involved in identifying the need for the research, the design of this research or any other stages? Is there any budget for public and consumer involvement? Is there any evidence of public involvement?

Research method – is the research question clear? Is the method valid? Do you need more information to answer these questions? Is the research new or has it been done before (e.g. has a systematic review been done)?

Translation – is it clear how this research could be useful? If not, how could it be better explained?

Research Funding – Who is paying for this research, is there a conflict of interest? Is the cost of this research justifiable when compared with other priorities? Who owns the findings, data and the ults (e.g. intellectual property)?

Dissemination - Will the results and data be published? Will this be publicly accessible? (this may help avoid research being repeated). Will any of the successes of involving the public be shared?

The questions below can be more helpful to ask for clinical research:

Patient experience – what issues might there be? Will this potentially improve the experience of future patients?

Information – How is information presented to potential participants? What is good, what could be improved? Does this affect ability to give informed consent? Are the risks and benefits clear? Is the timescale and commitment clear?

For more detailed information on critical appraisal, find some free resources from the Critical Appraisal Skills Programme at:

<http://www.casp-uk.net>

Resource 18: Like, comment, share? “Cinnamon and Honey”

This post was copied from a photo shared on Facebook in 2014, with the accompanying text below. The number of likes, shares and comments was from June 2015. **Would you like, comment or share?**



Like · Comment · Share

👍 66,010 people like this.

↗ 501,195 shares

💬 View previous comments 6 of 16,333

😊 Your name here? Omg!!!! Very useful info,,,great
1 hr · Like

People have asked me to re-post this! So here it is again!

Great information!! Cinnamon and Honey...! Drug companies won't like this one getting around.

Facts on Honey and Cinnamon:

It is found that a mix of honey and cinnamon cures most diseases. Honey is produced in most of the countries of the world. Scientists of today also note honey as very effective medicine for all kinds of diseases. Honey can be used without side effects which is also a plus. Today's science says that even though honey is sweet, when it is taken in the right dosage as a medicine, it does not harm even diabetic patients. Researched by western scientists:

HEART DISEASES: Make a paste of honey and cinnamon powder, put it on toast instead of jelly and jam and eat it regularly for breakfast. It reduces the cholesterol and could potentially save one from heart attack. Also, even if you have already had an attack studies show you could be kept miles away from the next attack. Regular use of cinnamon honey strengthens the heart beat. In America and Canada, various nursing homes have treated patients successfully and have found that as one ages the arteries and veins lose their flexibility and get clogged; honey and cinnamon revitalize the arteries and the veins.

ARTHRITIS: Arthritis patients can benefit by taking one cup of hot water with two tablespoons of honey and one small teaspoon of cinnamon powder. When taken daily even chronic arthritis can be cured. In a recent research conducted at the Copenhagen University, it was found that when the doctors treated their patients with a mixture of one tablespoon Honey and half teaspoon Cinnamon powder before breakfast, they found that within a week (out of the 200 people so treated) practically 73 patients were totally relieved of pain -- and within a month, most all the patients who could not walk or move around because of arthritis now started walking without pain.

BLADDER INFECTIONS: Take two tablespoons of cinnamon powder and one teaspoon of honey in a glass of lukewarm water and drink it. It destroys the germs in the bladder....who knew?

CHOLESTEROL: Two tablespoons of honey and three teaspoons of Cinnamon Powder mixed in 16 ounces of tea water given to a cholesterol patient was found to reduce the level of cholesterol in the blood by 10 percent within two hours. As mentioned for arthritic patients, when taken three times a day, any chronic cholesterol-could be cured. According to information received in the said Journal, pure honey taken with food daily relieves complaints of cholesterol.

COLDS: Those suffering from common or severe colds should take one tablespoon lukewarm honey with 1/4 spoon cinnamon powder daily for three days. This process will cure most chronic cough, cold, and, clear the sinuses, and it's delicious too!

UPSET STOMACH: Honey taken with cinnamon powder cures stomach ache and also is said to clear stomach ulcers from its root.

GAS: According to the studies done in India and Japan, it is revealed that when Honey is taken with cinnamon powder the stomach is relieved of gas.

IMMUNE SYSTEM: Daily use of honey and cinnamon powder strengthens the immune system and protects the body from bacterial and viral attacks. Scientists have found that honey has various vitamins and iron in large amounts. Constant use of Honey strengthens the white blood corpuscles (where DNA is contained) to fight bacterial and viral diseases.

INDIGESTION: Cinnamon powder sprinkled on two tablespoons of honey taken before food is eaten relieves acidity and digests the heaviest of meals

INFLUENZA: A scientist in Spain has proved that honey contains a natural 'Ingredient' which kills the influenza germs and saves the patient from flu.

LONGEVITY: Tea made with honey and cinnamon powder, when taken regularly, arrests the ravages of old age. Use four teaspoons of honey, one teaspoon of cinnamon powder, and three cups of boiling water to make a tea. Drink 1/4 cup, three to four times a day. It keeps the skin fresh and soft and arrests old age. Life spans increase and even a 100 year old will start performing the chores of a 20-year-old.

RASPY OR SORE THROAT: When throat has a tickle or is raspy, take one tablespoon of honey and sip until gone. Repeat every three hours until throat is without symptoms.

PIMPLES: Three tablespoons of honey and one teaspoon of cinnamon powder paste. Apply this paste on the pimples before sleeping and wash it off the next morning with warm water. When done daily for two weeks, it removes all pimples from the root.

SKIN INFECTIONS:Applying honey and cinnamon powder in equal parts on the affected parts cures eczema, ringworm and all types of skin Infections.

WEIGHT LOSS:Daily in the morning one half hour before breakfast and on an empty stomach, and at night before sleeping, drink honey and cinnamon powder boiled in one cup of water. When taken regularly, it reduces the weight of even the most obese person. Also, drinking this mixture regularly does not allow the fat to accumulate in the body even though the person may eat a high calorie diet.

FATIGUE: Recent studies have shown that the sugar content of honey is more helpful rather than being detrimental to the strength of the body. Senior citizens who take honey and cinnamon powder in equal parts are more alert and flexible. Dr. Milton, who has done research, says that a half tablespoon of honey taken in a glass of water and sprinkled with cinnamon powder, even when the vitality of the body starts to decrease, when taken daily after brushing and in the afternoon at about 3:00 P.M., the vitality of the body increases within a week.

BAD BREATH: People of South America, gargle with one teaspoon of honey and cinnamon powder mixed in hot water first thing in the morning so their breath stays fresh throughout the day.

HEARING LOSS: Daily morning and night honey and cinnamon powder, taken in equal parts restores hearing.

Make sure you SHARE this to save & find on your wall later.

Resource 19: Like, comment, share? “Cinnamon and Cochrane”

This information was published on the Cochrane website in 2013. It was the first result returned by Google after searching ‘cinnamon and ‘cochrane’. Some formatting has been changed to improve appearance.

http://www.cochrane.org/CD007170/ENDOC_cinnamon-for-diabetes-mellitus (15.6.15)



Trusted evidence.
Informed decisions.
Better health.

Search...



Our evidence

About us

Get involved

Cochrane Library



Cinnamon for diabetes mellitus

Diabetes mellitus is a chronic metabolic disorder. People with diabetes are known to be at greater risk of cardiovascular disease (including heart attack, stroke, and peripheral vascular disease such as acute or chronic ischaemia of a leg resulting in severe pain when walking short distances). There is also an increased risk of eye disease, kidney failure, nerve damage and sexual dysfunction when compared to the general population. Improvements in the regulation of blood sugar levels may help to reduce the risk of these complications.

Cinnamon bark has been shown in a number of animal studies to improve blood sugar levels, though its effect in humans is not too clear. Hence, the review authors set out to determine the effect of oral cinnamon extract on blood sugar and other outcomes. The authors identified 10 randomised controlled trials, which involved 577 participants with diabetes mellitus. Cinnamon was administered in tablet or capsule form, at a mean dose of 2 g daily, for four to 16 weeks. Generally, studies were not well conducted and lacked in quality.

The review authors found cinnamon to be no more effective than placebo, another active medication or no treatment in reducing glucose levels and glycosylated haemoglobin A1c (HbA1c), a long-term measurement of glucose control. None of the trials looked at health-related quality of life, morbidity, death from any cause or costs. Adverse reactions to cinnamon treatment were generally mild and infrequent.

Further trials investigating long-term benefits and risks of the use of cinnamon for diabetes mellitus are required. Rigorous study design, quality reporting of study methods, and consideration of important outcomes such as health-related quality of life and diabetes complications, are key areas in need of attention.

Authors' conclusions:

There is insufficient evidence to support the use of cinnamon for type 1 or type 2 diabetes mellitus. Further trials, which address the issues of allocation concealment and blinding, are now required. The inclusion of other important endpoints, such as health-related quality of life, diabetes complications and costs, is also needed.

Resource 20: Like, comment, share? “Cochrane and Honey”

After searching Google for ‘Cochrane’ and ‘honey’, two reviews were found. These were the first two results of 430,000.



Honey as a topical treatment for acute and chronic wounds.

We reviewed the evidence about the effects of applying honey on the healing of any kind of wound. We found 26 studies involving 3011 people with many different kinds of wounds. Honey was compared with many different treatments in the included studies.

The differences in wound types and comparators make it impossible to draw overall conclusions about the effects of honey on wound healing. The evidence for most comparisons is low or very low quality. This was largely because we thought that problems with the design of some of the studies made their results unreliable and for many outcomes there was only a small amount of information available. In some cases the results of the studies varied considerably.

There is high quality evidence that honey heals partial thickness burns around 4 to 5 days more quickly than conventional dressings. There is moderate quality evidence that honey is more effective than antiseptic followed by gauze for healing wounds infected after surgical operations.

It is not clear if honey is better or worse than other treatments for burns, mixed acute and chronic wounds, pressure ulcers, Fournier's gangrene, venous leg ulcers, minor acute wounds, diabetic foot ulcers and Leishmaniasis as most of the evidence that exists is of low or very low quality.

This evidence is current up to October 2014.

Authors' conclusions:

It is difficult to draw overall conclusions regarding the effects of honey as a topical treatment for wounds due to the heterogeneous nature of the patient populations and comparators studied and the mostly low quality of the evidence. The quality of the evidence was mainly downgraded for risk of bias and imprecision. Honey appears to heal partial thickness burns more quickly than conventional treatment (which included polyurethane film, paraffin gauze, soframycin-impregnated gauze, sterile linen and leaving the burns exposed) and infected post-operative wounds more quickly than antiseptics and gauze. Beyond these comparisons any evidence for differences in the effects of honey and comparators is of low or very low quality and does not form a robust basis for decision making.

Some formatting changed to improve appearance. Taken from: http://www.cochrane.org/CD005083/WOUNDS_honey-as-a-topical-treatment-for-acute-and-chronic-wounds (15.6.15) **Page 1 of 2.**

Honey for acute cough in children

Review question

We wanted to know if honey can reduce cough symptoms caused by bacteria and viruses in children.

Background

Cough is a cause for concern for parents and a major cause of outpatient visits in most clinics for both children and adults. Cough can affect quality of life, cause anxiety and affect sleep for parents and children. An immediate remedy is usually sought by the caregiver and patient. Cochrane reviews have reported on the effect of over-the-counter (OTC) cough medicines, but none have studied honey as a cough relief.

Honey is a sweet mixture of different types of carbohydrates, amino acids, flavonoids, vitamins and trace elements. Honey is believed to prevent the growth of bacteria, viruses and yeast, and reduce inflammation.

Study characteristics

We included three small randomised controlled trials involving 568 children, aged one to 18 years. The evidence is current to November 2014.

Key results

These small trials showed that honey may be better than 'no treatment' and placebo (a liquid that looks like and taste like honey, but is not honey) for cough relief. The evidence also showed that honey may be better than placebo in reducing worrying as a result of cough. However, it was no different to 'no treatment'. Honey allowed children and parents to sleep moderately better at night than 'no treatment'. The effects of honey and dextromethorphan on all cough symptoms were not different. Honey may be better than diphenhydramine for relieving and reducing the effect of cough on children. Honey may also allow parents and children to sleep better than diphenhydramine.

Diphenhydramine and dextromethorphan are both common ingredients in cough syrups. Parents of seven children given honey and two given dextromethorphan reported side effects that were not too serious, such as not falling asleep easily, or being very restless and over excited. Parents of three children in the diphenhydramine group reported that their children were often sleepy.

Quality of the evidence

As with other medicines, the benefit of honey should be considered alongside the harms. The limitation of this updated review is that only three studies were included. Two were small studies with a high chance that some of their results may not be very accurate.

It is also important to state that the use of honey in infants under the age of one is not advised because of their poor immunity against *Clostridium botulinum* (*C. botulinum*), a bacteria that causes infant botulism that may be present in honey.

Authors' conclusions:

Honey may be better than 'no treatment', diphenhydramine and placebo for the symptomatic relief of cough, but it is not better than dextromethorphan. None of the included studies assessed the effect of honey on 'cough duration' because intervention and follow-up were for one night only. There is no strong evidence for or against the use of honey.

Some formatting changed to improve appearance. Taken from:

http://www.cochrane.org/CD007094/ARI_honey-for-acute-cough-in-children (15.6.15) **Page 2 of 2.**

Resource 21: Like, comment, share? “That needs some WD-40”

Read this article and think about the following:

- What does the title make you think?
- Does the author voice their ideas or just those of others?
- Did the GPs carry out a ‘fair test’?
- Does the article cite any evidence based research?

Can WD-40 cure arthritis? Wacky home remedies put to the test by panel of doctors ... with surprising results

From the man who swears that garlic sandwiches give his love life a boost to the intrepid soul who thinks putting leeches on your bottom can cure deep vein thrombosis, the home remedies championed by the British can seem a motley bunch.

But few can be as bizarre as the claims made by builders Simon and Andy, who say that industrial lubricant WD-40 can help cure arthritis and ease a congested chest.

Currently, more than 10 million people suffer from arthritis in the UK alone, and the cost to the NHS runs into millions. Andy, who suffers from the condition, said: 'I went to the doctor and he prescribed me paracetamol for my arthritis. 'I sprayed WD-40 on my knees and it seemed to be better.' 'At first I thought he was completely mad and then I saw what it was doing for him so I thought I'd give it a go,' added fellow bricklayer Simon. 'It works for me. Thousands of bricklayers across the country can't be wrong!'

Unsurprisingly, the panel of medics were unimpressed. 'As far as I know, there's nothing in WD-40 that would have an effect on the joints apart from the cooling effect and the fact that rubbing helps,' said veteran GP, Dr. Ayan Panja. Asked if he was worried about any potentially toxic side-effects of using WD-40, Andy added: 'No, I'm not worried about toxins. If you do your research, you'll see there are fish oils in WD-40.'

Asked to comment on the claims, a spokesman for WD-40 said: 'This is one of the myths we regularly deal with.

'The WD-40 Company does not recommend the use of WD-40 Multi-Use Product for medical purposes, and knows no reason why it would be effective for arthritis pain relief. The product contains petroleum distillates and should be handled with the same precautions for any product containing this type of material.'

Among other unusual remedies featured in the documentary were amber necklaces and duct tape, thought to soothe teething pains and cure veruccas.

Although the duct tape was later proved to have an impressive effect on tackling veruccas, the amber beads did not impress the panel of GPs and, according to the medical professionals, does nothing to soothe teething pain in babies

This article was published in 2013 to promote a television programme. Some text has been removed for brevity.

<https://web.archive.org/save/http://www.dailymail.co.uk/femail/article-2470140/Can-WD-40-cure-arthritis-Wacky-home-remedies-test-panel-doctors-new-TV-Health-Freaks---surprising-results.html>

Resource 21b: Health herbs and evidence

Compare this photo (left) of health information (including references) in a 'health herb' shop with the information from Wikipedia. Please note, the Wikipedia entry has been edited for brevity (the references are number up to 18)



Tussilago

From Wikipedia, the free encyclopedia

Tussilago farfara, commonly known as coltsfoot, is a plant in the groundsel tribe within the sunflower family, native to Europe and Asia. It has traditionally had medicinal uses. The name "tussilago" is derived from the Latin *tussis*, meaning cough, and *ago*, meaning to cast or to act on.^{[2][3]} However, the discovery of toxic pyrrolizidine alkaloids in the plant has resulted in liverhealth concerns.

Traditional uses

Coltsfoot has been used in [herbal medicine](#)^[8] and has been consumed as a food product with some [confectionery](#) products, such as [Coltsfoot Rock](#). *Tussilago farfara* leaves have been used in the traditional Austrian medicine internally (as tea or syrup) or externally (directly applied) for treatment of disorders of the respiratory tract, skin, locomotor system, viral infections, flu, colds, fever, rheumatism and gout.^[11]

Toxicity

Tussilago farfara contains [tumorigenic pyrrolizidine alkaloids](#).^[12] [Senecionine](#) and [senkirkine](#), present in coltsfoot, have the highest [mutagenetic activity](#) of any pyrrolizidine alkaloid, tested using [Drosophila melanogaster](#) to produce a comparative [genotoxicity](#) test.^{[13][14]} There are documented cases of coltsfoot tea causing severe liver problems in an infant, and in another case, an infant developed liver disease and died because the mother drank tea containing coltsfoot during her pregnancy.^{[15][16]} In response the German government banned the sale of coltsfoot. [Clonal](#) plants of coltsfoot free of pyrrolizidine alkaloids were then developed in [Austria](#) and [Germany](#).^[17] This has resulted in the development of the registered variety *Tussilago farfara* 'Wien' which has no detectable levels of these alkaloids.^[18]

References

- ¹ ^ [Jump up to: a b c d Flann, C \(ed\) 2009+ Global Compositae Checklist](#)
- ² [Jump up](#) Capasso, Francesco (2011). "Capitolo M12: Droghe obsolete e/o poco studiate". *Farmacognosia: Botanica, chimica e farmacologia delle piante medicinali* (in Italian) (Seconda edizione ed.) (Springer Milan). p. 428. doi:10.1007/978-88-470-1652-1_30. ISBN 978-88-470-1652-1 http://books.google.com/books?id=qn5zb3_rqZIC&pg=PA428. *Tussilago*, dal latino *tussis* = tosse e *ago* = scaccio. Missing or empty |title= (help)

Resource 22: Example news story – ‘brain cancer is 'cured' after secretly being fed medical marijuana by his father’

Boy, two, with brain cancer is 'cured' after secretly being fed medical marijuana by his father

A desperate father whose son was suffering from a life-threatening brain tumour has revealed he gave him cannabis oil to ease his pain. And he has now apparently made a full recovery.

Cash Hyde, known as Cashy, was a perfectly healthy baby when he was born in June 2008 but became sick shortly before his second birthday.

At first he was misdiagnosed with glandular fever before his parents Mike and Kalli, from Missoula in Montana, were given the devastating news he had a serious brain tumour.

The little boy had to have arduous chemotherapy treatment to reduce the growth, which had drastic side effects including seizures and a blood infection.

His distraught parents were repeatedly told he was likely to succumb to the illness because the condition was so bad.

After one bout of high-dose chemotherapy, Cash was so weak he could not lift his head and was too sick to eat any solid food for 40 days.

It was at this point that Mr Hyde decided to take action and go down the route of medical marijuana to try to help his young son.

Cash's doctors refused to even discuss the option but his father went and sought authorisation elsewhere and then secretly administered it through his son's feeding tube.

He also told doctors to stop giving Cash the cocktail of anti-nausea drugs he had been taking - although he never told them what he was doing.

Mr Hyde told KXLY News that his son started looking better right away.

Mr Hyde said: 'He hadn't eaten a thing in 40 days - and, it was really incredible to watch him take a bite of a piece of cheese. It shows that he wants to live'.

He credits the cannabis oil with helping his son get through the chemo, and say Cash has now been declared cancer free by doctors.

The boy is now back and home and living the life of a typical young boy, playing with his elder brother Colty.

Medical marijuana is legal in some states, including Montana, but its use for children is poorly understood and quite rare.

The US federal government does not recognise the legality of using the drug for medical reasons and frequently clashes with states over the issue.

Mr Hyde told KXLY: 'It's very controversial, it's very scary. But, there's nothing more scary than losing your child.'

Article published on: 5 May 2011. Accessed 29.9.14 from: <http://www.dailymail.co.uk/health/article-1383240/Boy-brain-cancer-cured-secretly-fed-medical-marijuana-father.html23ixzz3EeyAYmtQ>. Some formatting has been changed.

Resource 23: Answering important questions using Maslow's 'hierarchy of needs'

Maslow's hierarchy claims that needs that are **low** in the hierarchy must be partially satisfied before needs that are **high** in the hierarchy can be prioritised. Think of a hierarchy as a pyramid, 'low' meaning a basic foundation.

The answers to the questions on the left lie at the very heart of good meetings. They've been placed in an order to approximate to the hierarchy. Discuss whether you agree with the questions being placed with the associated needs?

1. Will this be a good use of my time? 2. Why are we meeting anyway? 3. Are we going to accomplish something? Will this meeting help me make a difference?	Self Actualisation To find self fulfilment and realise one's potential
4. Will we stay on the topic or go off at a tangent?	Creative needs To create symmetry, order, and beauty
5. Is there an agenda?	Cognitive needs To know, learn explore, find out
6. What's expected of me? 7. What happened as a result of the last meeting? 8. Will we be making decisions and if so how?	Esteem needs To achieve, to be competent, gain approval and recognition, self-confidence, independence
9. Should I be here? Am I welcome? Do I feel I am being treated with respect?	Belongingness and love To be loved, liked needed or accepted by others
10. Where are the fire escapes? 11. Who are the other people?	Safety needs To be free of danger physically and emotionally – a sense of security
12. When will we take a break (e.g. to go to the toilet)? 13. Where is the food? When will we eat? 14. How long will this take? When are we leaving? (Will I need a strong coffee or a sleeping bag?)	Physiological needs Food, water, shelter, sleep, excretion

High

low (basic)

Questions adapted from Roberta's Rules of Order by Alice Collier Cochran Published by 2004.

Resource 24: Patient, consumer and public involvement

There are many things to think about when involving the public and patients in improving services – this document is intended to help ask the right questions for the right roles.

How to use this resource: Under ‘Assumptions and barriers’, read the questions and consider if these might be barriers to involving some people, and consider how you might overcome these. ‘Learning needs and support’ examines the role in more detail and asks questions about the support people might need support to develop.

Be clear what you want– do you want ‘patient’, ‘user’ or ‘carer’ involvement, a lay perspective or just anyone who can give their time? Consider who you might unintentionally exclude by using these terms and be clear what you mean by *engagement* or *involvement*.

Assumptions and barriers	Role Description	Learning needs & support
<ul style="list-style-type: none"> What commitment do you expect (time/financial implications) Have you asked people to think about their emotional readiness? Do you expect them to be reading and writing information and documents? Have you considered what formats might be appropriate? Are you assuming a good ability to speak and read English? Do you expect a certain educational background? 	<p>Consumer/Lay Leader: A person who speaks and acts on behalf of all members of the public, including patients and carers and who takes a leading role in representing other lay representatives. The role may involve holding people or organisations to account.</p> <p>Consumer/Lay representative: a member of the public (not a professional) who is a representative. They must speak and act on behalf of others. They may be guided by lay leaders but will be expected to take direct action to ensure that they are informed and able to represent the views of others.</p>	<p>How are they supported to be a representative?</p> <ul style="list-style-type: none"> How will they be gathering views? Will this involve research? Do they have a budget? Should they be paid? Is there admin and practical support (from an organisation?) Is there any training available? <p>Who is already doing this?</p> <ul style="list-style-type: none"> Are there any opportunities for them to be involved in peer support or have or be a buddy? What can be shared with other organisations? (E.g. learning, resources) <p>How are people involved?</p> <ul style="list-style-type: none"> Can people be involved in other ways? (e.g. is it face to face meetings? What can be done online, what cannot?)
<ul style="list-style-type: none"> Are the people who have engaged with you the only people who might be interested? 	<p>Interested and engaged consumers or members of the public: People who know about and/or are interested in decisions being made, but may take no direct action other than giving feedback, being involved in a public dialogue or signing petitions.</p>	<p>Could there be a need for translation?</p> <ul style="list-style-type: none"> Are there any groups or organisations who could support with this? <p>Remember: ‘public dialogue’ is not fully ‘representative’ but can give a strong indication of how the public at large feels</p>
<ul style="list-style-type: none"> It is easy to assume that people who are not engaged don’t want to be. Often they won’t even know how they can contribute or be involved Some may not be able to afford the time, caring responsibilities or travel. 	<p>Uninformed, disengaged or disinterested members of the public: people who, for what ever reason, are not engaged, informed or interested in influencing decision making or shaping the future of health and social services.</p>	<p>A majority of the population are in this category.</p> <ul style="list-style-type: none"> What information or support might some people need to help engage them or move them into other roles? What might make people move back into this role? (e.g. not seeing direct improvements, or too much of organisational change?)

Remember: roles are not always fixed, they are often just a way of articulating different things people can or should do. Tasks can be more focused. There is always a way for dedicated people to give their time and develop their skills, what ever the label or role description

Who I met (Name)	Contact details	What I want to talk to them about

Who I met (Name)	Contact details	What I want to talk to them about

Resource 25: Skills and knowledge grid

Knowledge is information you have in your head; a skill is the ability to use knowledge to achieve something.

Skills	Knowledge
Skills I already have (for example driving, speaking English)	Knowledge I already have (for example a knowledge of my community or local information resources)
Skills I have that I would like to develop (for example reading academic papers)	Knowledge I would like to develop (for example an understanding of reliable sources of evidence)
Skills I don't have but might need (for example using the internet to communicate)	Knowledge I might need (for example a knowledge of funding opportunities)
Skills I would be confident in helping others learn (for example, reviewing funding applications)	Knowledge I would be confident in sharing with others (for example, a good route for a bike ride)

Resource 26: Feedback Form

Why are we asking these questions?

The information collected will assist us in identifying how effective the learning event was in meeting participants' needs and help us to improve the learning events we offer. Any information you provide will be treated and held in accordance with appropriate data protection law.

Date: 23.6.15

Organisation/location: Cochrane Australia

Name:

Facilitator: Jack Nunn

Q1. Where did you hear about this event?

Q2. Please describe the area/s of the event that you found most valuable/most enjoyable:

Q3. Please describe the area/s of the event that you found least valuable/least enjoyable and/or areas that could have been developed further:

Q4. How do you intend to apply what you learnt on the event? What will you do differently? What do you think will be the effect of this?

Q5. What recommendations would you like to make for future events?

Please tick the relevant box to show whether you agree or disagree with the following statements.

Statement	Strongly agree	Agree	Don't know	Disagree	Strongly disagree
Did you feel that the event was useful?					
Did you feel that any learning needs you identified when registering were met?					
The learning resources used helped me to learn					
The trainer facilitator(s) were sufficiently knowledgeable about the subject					
The facilitator(s) used a range of activities to appeal to different learning styles					
The event was structured and paced well					
The facilitator(s) made the subject interesting and enjoyable					
The group of learners was managed well by the facilitator(s)					
I found the opportunity to learn and share with other people useful					
I learned what I expected to learn on this event					
I would recommend this event to others					
I was satisfied with the information and administrative support I received prior to the event					
The venue and refreshments were satisfactory					
Overall, I would rate this event as...(circle)	Excellent	Good	Average	Poor	Very poor

If you have any other comments or suggestions then please write them here or attach them:

Cochrane Australia may wish to follow up with you within a few months' time in order to understand whether this event helped you in the longer term and if so, in what ways. This may mean completing another short survey by telephone or online. If you would be willing to be re-contacted for this, please provide your contact details below, indicating your preferred method of contact:

Email address/Telephone:

Resource 27: Feedback - 'What are Systematic Reviews?' - Cochrane

We have created this short video to help explain what systematic reviews are. We would value feedback from anyone on this resource before we publish the final version. We hope to learn from your comments to improve this video.

Please provide your comments.

Do you have any ideas or suggestions that would improve this video? Do you think anything in particular was good or helped you learn?

Optional contact details

We may wish to follow up with some people about their feedback, to help us clarify how this resource can be improved. If you are happy for us to contact you, please provide your contact details.

Name:

Please share how would you prefer to be contacted? Telephone number, Email:

Do you wish to be informed when the final version of this video is published? (circle) yes / no

Helpful resources

Title	Link
SENSE ABOUT SCIENCE and Straight Statistics Making Sense of Statistics: “Just because something is statistically significant it doesn’t mean it is practically significant or of importance to society”	http://www.senseaboutscience.org/data/files/resources/1/MSofStatistics.pdf
Sense About Genetic Ancestry Testing	https://web.archive.org/web/20150611043824/http://www.senseaboutscience.org/data/files/resources/119/Sense-About-Genetic-Ancestry-Testing.pdf
Evidence based medicine matters	http://www.senseaboutscience.org/data/files/resources/124/Evidence-Based-Medicine-Matters.pdf
SENSE ABOUT SCIENCE MAKING SENSE OF UNCERTAINTY Why uncertainty is part of science	http://www.senseaboutscience.org/data/files/resources/127/SAS012_MSU_reprint_compressed.pdf
I’ve got nothing to lose by trying it	http://www.senseaboutscience.org/data/files/resources/136/Ive-got-nothing-to-lose_web.pdf
SENSE ABOUT SCIENCE MAKING SENSE OF DRUG SAFETY SCIENCE Investigating the science of side effects	http://www.senseaboutscience.org/data/files/resources/138/Making-Sense-of-Drug-Safety.pdf
Extraordinary claims need extraordinary evidence: Can you tell what diets are good for you and what’s good for a laugh?	http://www.senseaboutscience.org/data/files/resources/161/FINAL_SpoofDiets.pdf
“I DON’T KNOW WHAT TO BELIEVE...” Making sense of science stories	http://www.senseaboutscience.org/data/files/resources/16/IDontKnowWhatToBelieve_web2011.pdf
Systematic Reviews	http://www.senseaboutscience.org/data/files/resources/52/Sense-About-Systematic-Reviews.pdf

Additional resources



At the venue

On arrival at the venue you should check the following things. Please note that you should arrive at least 1 hour before the start of the session to allow time:

Safety and domestics – Find out where the fire exits are and if there are any planned fire drills or alarms. Locate the toilets and any disabled access toilets. Is there any food or tea and coffee? What time is this arriving? How is the temperature of the room controlled?

Welcome and signs - Is the room signed and easy to find? Does reception know the plans? Is anyone able to welcome and direct people?

The room

It is very important that you take charge of how the room is set out, remember, it is your session and you need to be as comfortable with it as much as the participants do.

The configuration of chairs can really affect the group dynamic. You may want to experiment until you find the seating that suits you best but remember that you will require delegates to write and work together and some may wish to take regular notes through the day so table or writing space may still be necessary. With all configurations it's important that everyone can see you, no delegates are hidden behind others and that each feels you can communicate with them both verbally and with eye contact. Sessions held on long boardroom style tables are the most difficult to work with and should be avoided when possible.

Ensure that anyone with sight or hearing problems is seated appropriately.

Effective configurations include:

- 'camp fire' arrangement - where everyone sits in an inward facing circle. This also avoids having tables in front of people.
- Half moon of chairs with the facilitator at the front.
- Banquet style – three small tables with groups sat around them. Be sure to mix people up regularly if you use this arrangement.

Ensure that the room is welcoming and tidy by making and food and drink accessible, drawing blinds to let light in, opening windows if it's stuffy.

Consider writing a welcome note, the name of the course and your name in a visible place.

You could place the 'Who I met' sheets around the room or on tables at this point.

As participants arrive

- Welcome people as they arrive, introduce yourself (and if necessary your co-facilitator) and thank them for coming. Agendas normally allow 30 min for arrival and settling in.
- Ask people to sign in or tick them off as they arrive. **The list of delegates must stay with you all day for reasons of fire safety.**
- Leave the broad introduction until all are present or until the scheduled start time.
- Welcome people and thank them for coming and give a brief introduction about the day.
- Get people to say their names, what they'd like to learn or gain from the training.
- If appropriate, ask them to include any experience of an illness they want to share or what motivated them to come to the day.
- Write what people want to learn (on a flip chart or something similar) and return to this at the end of the day to confirm people learned what they expected.
- If someone says something that will not be covered in the session, don't write it down and mention it won't be included
- Clarify course content, format and mutual expectations of the day and ask if anyone has any anxieties about the day.
- Draw pictures of the words in **bold** to prompt a discussion and consensus about the following:



- **Fire exit and alarms** – make sure people know about these
- **Toilets** – do people know where they are?
- **Clock** – agree times for lunch, breaks and finishing. Does anyone need to leave early (mention they'll need to fill in an evaluation form before they do).
- **A sealed envelope** for a discussion on confidentiality
- **Spelling tick** – all spelling is korrekt
- **Thermometer** – people should say if the environment of the room is uncomfortable
- **TLAs** (with a line through it) – This stands for 'three letter acronyms'. Please try to avoid using any acronyms as they can alienate those who don't know them
- **Hand-up** – mention that people should feel free to say anything at any point, but some people find this hard and if they prefer they can raise their hands to signal they want to speak

Why: By evaluating the impact of research and public involvement in research, you can help to build an evidence base and let others know about what worked well and what could be improved.

How- involve the public in:

- How you are going to monitor and evaluate the impact of the research, and the public involvement in the research!
- Writing up (and publishing) an evaluation of the public involvement itself!

Example: The UK Clinical Research Collaboration published a [report](#) of a project to evaluate patient and public involvement in research.

How –
Work in partnership to plan the implementation as early as possible.

Example: Service user researchers and a nursing researcher co-delivered training in therapeutic interventions to staff teams in a mental health trust (St George's, University of London)

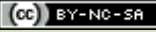
Why: Members of the public involved in research are often passionate to ensure that action happens as a result of the research and are often able to establish relationships with key agencies and policy makers.

Why: Involving the public in helping to identify and prioritise research allows them to influence what will be researched and lets researchers check that research priorities are the same as those of people who have the conditions being researched or who use relevant services.

How: use a mixture of face to face and online tools to facilitate discussions with existing reference groups and networks. This can include inviting the public to an event or researchers attending public and patient forums and events

Example: The James Lind Alliance facilitates Priority Setting Partnerships. These partnerships bring patients, carers and clinicians together to identify and prioritise the treatment uncertainties which they agree are the most important for research.

#	P	Size
21	1/1	A3



Why: Many funding organisations now involve members of the public in commissioning research. This gives a broader perspective to the review process, by considering the issues that are important from a public perspective.

How:

- Involve members of the public in reviewing research proposals
- Have a members of the public on research commissioning panels or boards
- **Research grant applications**
- Organisations representing groups or conditions commissioning research.

Example: After asking people affected by multiple sclerosis, the MS Society decided to fund research into improving the day-to-day lives of the people it affects, as well as biomedical research.

Identifying and prioritising

Commissioning

Example: The 'Workplace Impact of Supported Employment Study' involved service users in the design of study through a local group. The purpose was to investigate the impact of Individual Placement and Support in a mental health catchment area

Designing and managing

How- involve the public in:

- Reviewing proposals and commenting on any potential difficulties in the design
- Developing research tools, information such as questionnaires, patient information sheets and consent forms
- Monitoring and managing the research process

Why: Involving members of the public in the design of research helps to ensure that the research is relevant to the needs of people, helps ensure the research question and outcomes are clear and ensures the research method has thought about the needs of anybody participating in the research.

Undertaking

Example: The Macmillan Listening Study trained people affected by cancer to carry out research to identify the cancer research priorities of people affected by cancer

How- involve the public in:

- Gathering and reviewing documentary evidence
- Carrying out interviews and running focus groups
- Developing research tools and information
- Analysing and interpreting the data or results of research.

Why: Involving members of the public in undertaking research can mean that research is carried out by people with a personal experience of the area of research or with relevant knowledge of a particular culture.

Analysing and interpreting

Example: The University of Western Australia founded a programme to support researchers, consumers and the community to work in partnership to make decisions about research development using linked data.

How- involve the public in:

- Interpreting and commenting on results
- Analysing publicly available open data

Why: Dissemination is critical is the knowledge gained from the research is to have an impact. Good dissemination can also help identify the need for further research in a particular area.

Example: The Eve Appeal sent a letter to everyone who took part in the UKCTOCS screening trial and offered them the chance to continue to receive updates.

How- involve the public in:

- Developing the dissemination plan
- Summarising the research findings in clear and accessible ways
- Presenting at conferences, speaking to patients, support groups and service providers
- Publication in **open access** peer-reviewed scientific journals
- Publishing on websites, writing to journalists, creating leaflets for waiting rooms or community centres.

Why: Publishing linked data and results in the public domain allows others to analyse any findings and facilitates a range of people to give their time, scrutiny and perspective to the research

Identify topics

Prioritise topics

Commission or fund proposals

Design research

Manage research

Collect data

Analyse and interpret data

Disseminate

Implement or translate findings

Evaluate impact

Acknowledgments

This manual was created by Jack Nunn for Cochrane Australia, with the support of the Cochrane Consumers and Communication Review Group (CCCRG).

Thank you to Sophie Hill, Anneliese Synnot, Kelly Allen and Steve McDonald for their support and guidance in creating this manual.

Please send any feedback to Jack.Nunn@latrobe.edu.au or via Twitter: [@jacknunn](https://twitter.com/jacknunn)

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Some of the resources in this manual have been adapted from:

‘[Building Research Partnerships](#)’, created by Macmillan Cancer Support and available under the same licence.